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ABSTRACT

This report examines the need for inclusion of people with developmental disabilities in community life and describes activities of service providers in Minnesota toward meeting that goal. Part 1 reviews issues of eligibility involved in the exclusion of individuals with developmental disabilities from services. The lives of people who are unserved or underserved and potential changes in eligibility criteria are discussed, as are underlying issues of power and resources. Part 2 examines critical issues including values, home and family life, education, employment, and funding problems. Part 3 focuses on empowerment of individuals and the need for a system accountable to the individual, including comprehensive planning, assessment, support, and evaluation components. The report includes photographs, public testimony, statistical data, and policy recommendations. (PB)

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REPORT

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# "The heart of community is inclusion..."

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JANUARY 1, 1990

Macedonio "Mac" goes to and from his job by bus. He also likes to visit the local library and the corner cafe once a week.

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This report is prepared to fulfill requirements of Public Law 100-146 (The Developmental Disabilities Assistance and Bill of Rights Act). The reader is referred to other reports published by the Minnesota Governor's Planning Council on Developmental Disabilities for additional information and complete references.

"The heart of community is inclusion..."

Mike bowls once a week in an integrated outing.

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This report examines the need for inclusion and for the knowledge and information that support inclusion. Our analysis is divided into three parts:

*PART ONE*

**The Dynamics of Eligibility**

*PART TWO*

**Values, Issues and Funding**

*PART THREE*

**Accountability and Power for Individuals**

In Part One, we review issues of eligibility which are involved in the exclusion of individuals with developmental disabilities from services. Underlying that analysis are issues of power — information, justice and advocacy. Public testimony indicates that an even greater issue is the availability of services. Those who are ineligible do not receive services, but often the same is true for those who are eligible. Eligibility often means "eligible to wait."

In Part Two, we examine the critical issues for the 1990s — having a home and family life; learning, and working; making sense out of the world; and being supported to participate in the community. We also analyze how money is spent. For the most part, funds are allocated to the system rather than to people. In such a system, there is minimal accountability to those served, not served, and underserved.

We found in our analysis of issues and funding that not much has changed over the last few years. There continues to be a wide gap between what we know to be both possible and desirable for people with developmental disabilities, and the situations in which people currently find themselves. There is a gap between policy and practice.

To bridge that gap requires great effort. One of the primary requirements is to build a system which is truly accountable to persons with developmental disabilities. Accountability implies power. Accountability to the person implies that the person with a developmental disability has power.

Part Three explores some of the ways in which individuals are empowered — to have control over their own lives, and to hold services and systems accountable for actions taken.

An accountable system is the goal of the Minnesota Govenor's Planning Council on Developmental Disabilities. Power to individuals and families is a primary vehicle for achieving that goal. As you will read, through testimony at public hearings, results of a consumer satisfaction survey, research conducted in Minnesota, and our own analysis, it is clear that the goal is not only important, but has not been achieved for most Minnesotans.

Value systems change slowly and incrementally. It is difficult, if not impossible, to legislate values. But as all children grow up together and experience inclusion in school systems and community settings, values will change. The play friends of today will be the doctors, lawyers, legislators, and business persons of tommorrow.

If people with developmental disabilities are to be included in the community, there is a critical need for more collaborative efforts between public and private organizations, government, and education. We no longer can do it alone. We must all work together.

*We need to work together to enable individuals with even the most severe disabilities to begin to conquer and replace:*

*Joblessness with a real job at a real wage;*

*Inaccessibility with true access;*

*Confusion, anger and resentment with choice;*

*Apathy with activism;*

*(Robert Williams, 1989)*

To understand the dynamics of eligibility, we must first look at the critical populations of individuals who are **unserved** or are **underserved** by the service system. In addition to the federal definition which focuses on the nature of disability, there are a number of other ways we can define these terms.

## People Who Are Unserved And Underserved

One way to define **underserved** is "those individuals who are currently receiving services, but whose needs are not being met by those services." Using this definition, we can identify two major groups who are underserved:

- Those who are living, learning, or working in environments which congregate and segregate them, and who are not actively assisted in being present and participating in the community.
- Those who are being supported to be merely present in the community, but are not being supported to develop and sustain relationships with typical citizens and to participate in the life of the community.

We have learned from testimony and public hearings that **unserved and underserved** can also be defined as "receiving fewer services than others." There are clear indications that members of the following groups or communities receive less or far less service than others:

- People with epilepsy, cerebral palsy, autism, and head trauma.
- People who require personal assistance.
- People who live in rural areas, and/or areas outside the seven-county metropolitan area.
- Members of specific ethnic groups.

Emily plays in the backyard at her cousin's house with confidence and adventurous energy.

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## Changes in Eligibility Criteria

We have seen significant changes occur in the objective criteria used to determine eligibility. Over time, criteria have been expanded to ensure that persons with developmental disabilities, not just those labeled mentally retarded, are eligible for services. There is also an increased emphasis on individuals with more challenging needs being eligible for existing services. As a result, eligibility criteria now cover a greater number of groups of individuals, where group is defined by type or severity of disability.

Why have these changes occurred? Changes result from a growing recognition of **rights** and **expectations.** Increasingly, "type of disability" is seen as prohibited grounds for discrimination. There is less tolerance of individuals being excluded from services because their "other disability" is viewed as making them "hard to serve." Today, people with severe and multiple disabilities, and with more challenging needs, are seen as capable of benefiting from services, especially in the areas of education and rehabilitation.

Changes in criteria are reflected in the Minnesota statute defining developmental disabilities. The definition includes "related conditions" which are "closely related to mental retardation" in the sense that impairment is related to intellectual functioning, or adaptive behavior "similar to that of persons with mental retardation."

Because the emphasis is on "developmental," the definition includes criteria such as age of onset (in Minnesota, before age 22) and length of impairment (likely to continue indefinitely). Taken together, these elements of the definition include many people but also exclude others. Specifically excluded are individuals with an impairment that:

- occurs after the age of 22
- is not clearly lifelong
- does not correspond to mental retardation

There are two broad approaches to the definitional issue which would ensure, either alone or in combination, the inclusion of greater numbers of persons with developmental disabilities:

- A definition based on any disability listed as eligible for Social Security Disability Insurance, and/or
- A definition based on need for support or limitation in activity.

### *PUBLIC TESTIMONY*

*Testimony at public hearings identified a number of groups considered unserved or underserved:*

*"Individuals with developmental disabilities who are aging need additional supports to overcome double jeopardy."*

*"More services are needed for people with both mental retardation and mental illness."*

*"The most difficult people to reach are those with borderline intelligence. Because of the stigma attached to many services, they will refuse such services."*

*"Adults with developmental disabilities who reside with their elderly parents."*

*"People with brain injury and spinal cord injury are not getting the attention they need. These people don't belong in nursing homes."*

*"People with epilepsy need better access to legal advocacy and employment."*

*"There is not enough outreach to those who could benefit from services. County social services waits until there is a crisis and then the person usually ends up in the most restrictive setting."*

Mike will graduate from High School this spring. His goals are to live independently and to become a peer advocate.

*In reviewing eligibility criteria of state and federal programs, we concluded that every agency has its own definition of eligibility based on "handicap" or "disability" or "impairment." None of the definitions are identical across agencies. In addition to a diagnosis, eligibility is often determined by other requirements such as income, age limits, team decisions, or specific needs or requirements.*



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We can reach several conclusions about estimating need based on type of disability:

- Minnesota does not have a centralized waiting list that provides an accurate estimate of need based on functional limitations or urgency of need;
- Any waiting list data reported by providers contain duplicated numbers;
- The consumer survey represents volunteers and is not a scientific sample. The survey results do not provide an accurate estimate of need; and
- Various state studies have been undertaken to estimate number of people served and expenditures, but rarely do these studies focus on outcomes such as changes in independence, productivity, and integration. Nor do these studies provide an accurate estimate of need based on type of disability.

*"Census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally;*

*(Americans with Disabilities Act, 1989)*

## Eligibility: An Issue Of Power

In addition to objective criteria and definitional issues, there are other and equally powerful dynamics involved in eligibility and issues of exclusion. These other factors can be summarized in three terms:

KNOWLEDGE

DISCRETIONARY JUDGMENTS

SELF SELECTION

**KNOWLEDGE:**

In many ways, eligibility involves decisions by service providers about who is eligible for services. These "gatekeepers" determine who gets through the door. Eligibility criteria are the rules by which gatekeepers decide to open the door.

Another dimension to the issue of knowledge is the process by which individuals come to the door, regardless of whether or not it is opened for them.

We believe there are many Minnesotans with developmental disabilities, or families, who **are not aware of available services, and of services for which they might be eligible**.

There is no widely disseminated, easily accessible, or comprehensive listing of services, and of alternative approaches to service delivery, available to Minnesotans with developmental disabilities.

As a result, individuals must rely on the knowledge and judgments of those with whom they are in contact to get such information. We know from years of experience and public testimony that within both lay and professional communities, there are serious gaps in knowledge about:

- What services are available, and
- To whom those services are available.

This is often true for both specific services designed and targeted for people with developmental disabilities, and generic services typically available to the general public including people with disabilities.

Generic services and programs are often linked to two problems relating to knowledge. First, providers of a generic service may not view it as applicable to people with disabilities. As a result, they do not advertise the service to such individuals, or think about them when services are developed or implemented. Second, lay people and professionals do not view the generic service as available or appropriate for people with developmental disabilities or their families. As a result, they do not approach the program or service.

As a consequence, individuals do not refer themselves to services, nor are they referred by professionals.

**DISCRETIONARY JUDGMENTS:**

With little information, individuals and families must rely on the knowledge and judgments of others as to what services are available and appropriate. By and large, the "others" are professionals, either as sources of referrals to other services or as the gatekeepers to those services.

Obviously, when professionals are not aware of services, they cannot inform individuals or families of these services. Other factors determine whether or not professionals refer people to services such as:

- Their assumptions about service availability may lead to professionals not informing individuals or families about services (e.g. long waiting lists, financial restrictions, caseloads).
- Their assumptions about the appropriateness of a service may lead to professionals not informing individuals and families about services (e.g. the person will not benefit from the service, the service does not respond well to individuals with certain types of disabilities, etc.).

These factors influence whether or not individuals "get to the gates."

Once individuals are at the gate, however, a range of other discretionary judgments enter into the picture. While the "gatekeepers" may determine that an individual is eligible for a service, they also have discretion over the range of options offered:

- Assigning a priority to the individual.
- Determining whether the individual is served immediately or placed on a waiting list.
- Offering a limited or wide range of the services offered by the agency.
- Offering services which are acceptable or unacceptable to the individual or family.
- Offering to "go to bat" for the individual or family in order to get more resources so service can be provided.

**SELF SELECTION:**

A third aspect of eligibility and inclusion/exclusion is the perceptions of individuals and families about the services they choose. In simple terms, there are three key questions related to eligibility:

- Do I need this type of service?
- Am I eligible for it?
- If I get the particular service offered, will it meet my needs?

The eligibility of people with developmental disabilities is a JUSTICE issue. The extent to which there is a match between the service offered and the needs of the individual is a QUALITY issue.

Two factors are involved when individuals and families choose not to knock at the doors of services:

- The service is viewed as inappropriate and not requested. The individual may need the type of service (e.g., residential), but the nature of the service provided is seen as not meeting the individual's needs (e.g., too restrictive, segregated, congregated, etc.).
- The service is regarded as appropriate but inaccessible (waiting lists, not enough funding, not available in the individual's community of choice, etc.).

Both of these judgments reverse eligibility criteria: the service is viewed as ineligible to serve the person.

Cutting through our analysis of eligibility in the state of Minnesota are fundamental issues of power:

- **Information:** Do citizens and professionals have information about what is available for people with disabilities in both the human services system and more generic systems?
- **Justice:** Are citizens who are members of a specific group of people (people with developmental disabilities, people with more or less challenging needs, people who are seen as capable of benefiting from a service) eligible for services?
- **Advocacy and vigilance:** Are citizens and professionals empowered to gain access to services which meet their needs and to adapt those services which could meet their needs?

## Recommendation

We recommend that each existing agency work to ensure that needs of all people who are unserved and underserved are met. There is no single agency that can accomplish this mission alone.

*Decision makers responsible for human services must answer three questions: How can we insure sufficient cash income for people with disabilities?*

*How can we increase options for direct control of the specific supports people require?*

*How can we invest in activities that build inclusive community?*

*(John O'Brien, 1989)*

Much of what we present in this report will be familiar to citizens of Minnesota. The discussions which follow will read like previous reports. What we described and analyzed in the past is still a reality.

There is still a tremendous gap between what we know to be possible and desirable, and what people with developmental disabilities and their families experience on a day to day, and year to year basis.

The dark side of our analysis is clear — the prevailing state of affairs described in 1983, 1984, 1987, and 1989 is the same.

The bright side of our analysis is becoming clear — Minnesotans and others have embarked on a number of new undertakings which have a promising future of inclusion. The values and reasonings which underpin what we described in 1987 as a "new way of thinking" are increasingly determining what we do, and our judgment of how well we are doing.

*January 1983: In **"Developmental Disabilities and Public Policy: A Review for Policymakers,"** we illustrated trends in community services and identified policy issues for the 1980s.*

*March 1984: In **"Toward a Developmental Disabilities Policy Agenda — Assuring Futures of Quality,"** we discussed the relationship among values, policies and services provided to people with developmental disabilities. We discussed what our status was at that time in a number of areas; presented examples of what was possible; and recommended some goals for the future.*

*January 1987: In **"A New Way of Thinking,"** we again reviewed our status and described new ways of thinking about people, services and communities. These new ways hold the promise of transforming the ways we support people with developmental disabilities in regular schools, regular homes, and regular jobs.*

## What's It All About: Values

In the *Developmental Disabilities Assistance and Bill of Rights Act*, Congress found that there are more than two million people with developmental disabilities in the United States. Not withstanding their severe disabilities, these persons have capabilities, competencies, personal needs and preferences.

It is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens.

In 1989, the number of people with developmental disabilities in the State of Minnesota (depending on the prevalence rates used to estimate) range from 43,070 to 103,368.

In *A New Way of Thinking* we described new ways of thinking about people with disabilities, about services and communities in Minnesota. We said that people with developmental disabilities are, first and foremost, people with ability. Without special assistance some people with developmental disabilities cannot take advantage of the freedoms and opportunities of our society. They are, however, fundamentally more like the rest of the population than they are different from it.

*"The most important lesson of all: That I did not need to be perfect to be loved. That no one does."*

*(Alice Walker)*

Mike has real success and sometimes real failures, but as long as he is not treated "special" he keeps on trying.

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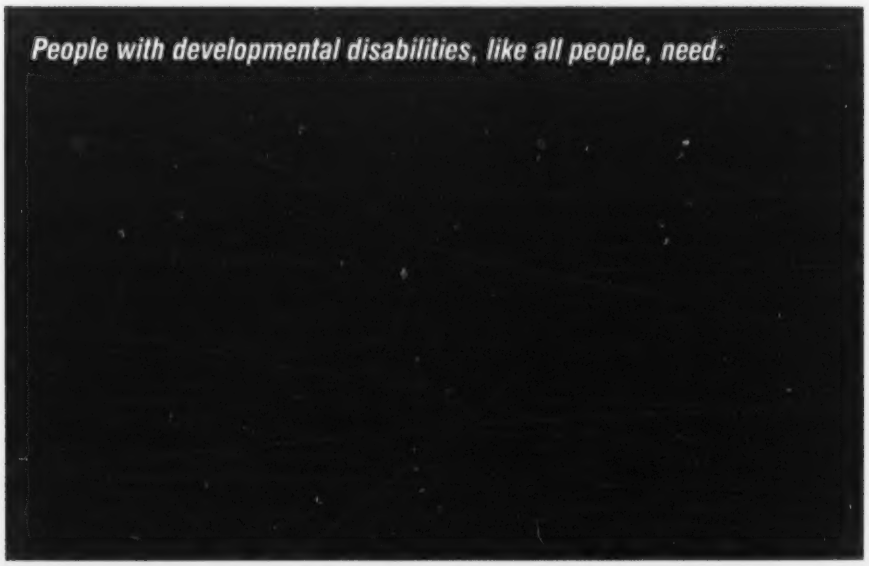


We have learned that services are most successful when basic needs are addressed. In responding to these basic needs, our hope for the future and our thoughts about the quality of our lives are often concerned with three basic issues: HAVING A HOME, not just a roof over our heads; LEARNING SKILLS which are useful to our lives and careers of WORKING, not just keeping busy. There is a fourth basic issue which gives vitality and fullness to our lives: DEVELOPING AND SUSTAINING RELATIONSHIPS with people who depend on us and upon whom we can depend.

People with developmental disabilities often are more handicapped by the environment than by their disabilities. The most dramatic shift in our way of thinking is the recognition that social and physical environments are often a greater issue than abilities and disabilities.

There is a new way of thinking about how, where, and with whom people with developmental disabilities can live, learn and work. This new way of thinking has involved a shift from a preoccupation with preparation, care and treatment to a concentration on supporting participation, building on capabilities, adapting environments, and building relationships. The new way of thinking means assisting individuals and families in identifying what is important to them, and empowering them with decision-making and spending authority to act upon those choices.

***59.5** percent of individuals with developmental disabilities lived in settings which clearly do not meet the definition of "a real home."*

***Table 1:***
Outlined below are the numbers and proportions of Minnesotans with developmental disabilities in publicly subsidized living arrangements in Fiscal Year 1988.

*Home and Community Based Waiver (1,565)* ***12.9%***

*Family Subsidy (410)* ***3.4%***

*Semi-Independent Living (1,075)* ***8.9%***

*Adult Foster Care (962)* ***7.9%***

*Child Foster Care (890)* ***7.4%***

*Regional Centers (1,498)* ***12.4%***

*Community ICFs/MR (4,748)* ***39.3%***

*Nursing Homes (948)* ***7.8%***

***TOTAL NUMBER OF PERSONS 12,096***

Emily enjoys trying out new toys and books her mom gets from a lending library.

In *A New Way of Thinking* we described a real home as a place to live the most personal moments of our lives. A home provides security and comfort, allows us to make choices and express ourselves. The people who share our homes are usually the people with whom we choose to spend time. Having a real home is as important to people with developmental disabilities as it is for everyone else. For children, home means parents who build an atmosphere of love, affection, security, and comfort. For all of us, home means moral and material security and a place to invite friends.

Community and family support services can assist persons with developmental disabilities to develop or maintain suitable homes in the community. Family and members of the community can play a central role in enhancing the lives of persons with developmental disabilities, especially when the family is provided with necessary support services that:

- strengthen the family's role as primary caregivers;
- prevent inappropriate out-of-home placements and maintain family unity;
- reunite families with members who have been placed out of the home.



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## Where We Are

### ICF-MR SERVICE:

The Medical Assistance Program has funded institutional services and community-based residential services since 1971. Minnesota has used this federally sponsored program to fund the development of over 330 ICFs-MR.

According to Braddock (1988), Minnesota spent $315.7 million in Fiscal Year 1988 for services for persons with developmental disabilities. The Medical Assistance program accounted for 72.7 percent of these expenditures (including state and county match). There are problems, however, in relying too heavily on Medical Assistance:

- Fiscal incentive to state and county authorities is toward this program and not toward family support services.
- Without Medicaid reform there is little incentive to shift funds to families and support services.
- The Medicaid program historically has relied on institutional and large congregate care settings. Institutional services consumed 33 percent of service expenditures while community services received nearly 67 percent of service dollars. In-home family support received less than one percent of these dollars.
- Funds do not start with family support nor move with persons from congregate care settings to support services.

The 1989 Minnesota Legislature passed legislation enabling 1,250 persons (of the approximate 1,450 people who still live in regional treatment centers) to move to community programs during the next decade. Twenty-four residential and 14 day programs serving persons with developmental disabilities will be developed in the next two years that will employ current state employees. The community service system will be enhanced by allocating 150 professional staff for crisis management teams, and 25 professional staff to provide regional technical assistance. Discharge plans will allow active participation of the family with the right to appeal the discharge.

### NURSING HOMES:

At the federal level, the Omnibus Budget Reconciliation Act of 1987 required states to move persons with developmental disabilities who were inappropriately placed in nursing homes to more appropriate services by April 1, 1990. In 1987, there were an estimated 1,200 persons with mental retardation or related conditions living in nursing homes funded by Medical Assistance. Since 1987, 164 persons have been relocated to other services (ICF-MR, Home and Community Based Waiver, and Semi-Independent Living Services), and 110 are waiting placement. There are an additional 275 persons who need to be moved.

## Critical Indicators For the Future

There are hundreds of detailed questions that individuals can ask about the quality of their home and home life. A publication by the Minnesota Govenor's Planning Council on Developmental Disabilities entitled, *Read My Lips: It's My Choice* has an extensive checklist of the questions a person should ask in choosing where to live. Listed on this page are some critical questions that need to be answered affirmatively by the individual with a disability and those who are close to the individual:

The boys...everyday a new adventure in the neighborhood... everyday a new challenge to conquer.

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**HOME AND COMMUNITY BASED WAIVER:**

Minnesota received approval for a Home and Community Based Waiver in 1984. By 1988 we had served over 1,600 persons. This program offers a variety of community services to persons at risk of institutional placement. In 1988, expenditures totaled $25 million, or 9.9 percent of total expenditures. Drawbacks to this program are:

- The cap on payments, as stated in the waiver application, often excludes persons with severe needs who cost more to serve than the "average."
- Current providers may screen applicants in order to serve only those persons they can afford to serve.
- Lack of funds to meet individual needs can encourage services in restricted settings.
- Current funding structures do not encourage serving underserved or unserved persons as resources are allocated on a "first come, first served basis."

**PERMANENCY PLANNING:**

Concerns have arisen over inappropriate placement of children. Although Permanency Planning Grants to Counties are intended to assure that children live with families that offer a safe, permanent relationship with nurturing parents or caretakers, there are indications that children with disabilities are placed out of the home for extended periods with no plan to return home. By far the largest number of children in long term substitute care are mentally retarded. Over 87 percent of the children with disabilities have been in substitute and adoptive care for more than three years.

**CONSUMER SURVEY:**

The consumer satisfaction survey, conducted in the summer of 1988, provides additional information on "where we are." Survey responses from 134 children and 108 adults on questions about home and family life indicated that:

- All children who lived at home with parents and received family support reported satisfaction.
- Children who lived in a congregate care facility (ICF-MR or state institution) tended to be dissatisfied due to poor quality of care, inappropriate services, and ineffective services.
- Like children, adults who lived in a more typical family setting (i.e., supervised apartment, room and board, or living with relatives) were 100 percent satisfied.
- Dissatisfaction was highest for adults with physical or emotional disabilities who lived in their own apartments or one of the regional treatment centers. For adults in their own apartments, reasons for dissatisfaction ranged from inaccessible housing, unaffordable housing, and lack of integration. Reasons for dissatisfaction among adults living in regional treatment centers were poor care, the desire to live closer to family, and the desire to live independently.
- Questions about homemaking assistance and housing subsidy indicated a high degree of satisfaction with non-congregated housing, more so than satisfaction percentages expressed for congregate care.

## *PUBLIC TESTIMONY*

*"Employment opportunities often fall apart because there is no housing."*

*"I would be frustrated if people were to be told where to live because of a slot being available. We have many people who could live in the community out of the ICF-MR."*

*"There are currently 500 people on the waiting list for SILS around the state. This does not include people who are currently living at home nor youngsters who will be coming out of school, or older individuals living in more restrictive settings."*

*"People who have their children living with them are underserved. Services are hard to get, and if you do get them, you have to find your own respite care or child care providers. Wages are low. It is very difficult to find qualified and/or trained help."*

*"The county is telling me to put my kids into foster care because I have no help. I am finding it hard to deal with all three kids. Foster parents are getting respite care before natural parents."*

*"Staff and providers do not have enough training to serve persons with severe disabilities. There is a need to put more dollars into training. Turnover of staff in community facilities can be as high as 100 percent. This can be turned around with better training and better wages."*

## Recommendations

We must develop and implement COMPREHENSIVE HOUSING AND HOME LIVING for persons with disabilities to ensure that:

- Children will live with and as members of families, not in group or congregate settings;
- Adults will have a choice in the style, location, and nature of their housing, and be assured of tenure in that housing;
- Support services and adaptations will be provided so that individuals can live in the housing of their choice;
- The use of existing housing stock will be emphasized, and that new housing is developed which is "typical" in nature;
- Individuals will have the right to choose the people with whom they live;
- Accountability (to prevent abuse and neglect) will be based on the degree to which an individual's housing and home life is developed and supported so as to maximize the individual's independence, productivity, and integration into the life of the community; and
- Eligibility for supportive housing (typical housing with special support, rather than special housing) will be based on the need for support, rather than any diagnosis or label which implies the need for support.
- Priority attention will be given to the development of new housing and home support options for individuals who are currently unserved or underserved, rather than placing such individuals in existing services that do not respond to their needs.
- Federal and state funding must be reformed to ensure individuals with physical disabilities, emotional problems, and sensory impairments have full access and that these programs support individuals and their families.

In *A New Way Of Thinking* we stated that real learning is lifelong. It means learning to understand ourselves. Learning means developing skills which are useful both to us as individuals and as members of communities. The people with whom we learn are also teachers. Many become friends we can count on throughout our lives.

Federal law established the basis for special education in public schools. Included in that law was the idea of a continuum of alternative placements ranging from residential schools to regular classrooms. Pitfalls of this "least restrictive environment" (LRE) continuum as identified in an article by Taylor (1989) included:

- It legitimizes the most restrictive environment as a service for persons with the most "severe" needs.
- It confuses segregation and integration on the one hand with intensity of services on the other hand.
- It is based on a "readiness model."
- It supports the primacy of professional decision-making, rather than individual freedom of choice.



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In our society, learning is a valued activity, important to the development of individuals. Growth, learning and belonging are important to all children, but especially to children with developmental disabilities. If these children are to participate and contribute to their communities, it is essential that their education be efficient and effective. Many children with developmental disabilities have difficulty learning. It is critical that we develop strategies and approaches to prepare children for life and enhance their individual capabilities.

## Where We Are

By 1988, early childhood special education had expanded so that school districts were serving children with developmental disabilities from birth to age 21 (see Table 2). Tables 3 and 4 provide a breakdown of special education by educational setting and program area.

Jenny is greeted each morning by a student aide and her advocate. They help her get off the bus and to her locker before first period.

***Table 2:***
*Number of children in early childhood special education:*

| | |
|---|---|
| *Birth to Age 2* | ***1,195*** |
| *Age 3 to 5* | ***4,289*** |
| *Age 6 to 8* | ***195*** |
| ***TOTAL*** | ***5,679*** |

***Table 3:***
*During the 1985-1986 school year, the percent of students by educational setting was as follows:*

*Regular classroom* ***12.62%***
*Resource room* ***62.69%***
*Separate classes* ***9.83%***
*Public separate facility* ***12.28%***
*Private separate facility* ***0.00%***
*Public residential facility* ***0.47%***
*Correctional facility* ***0.03%***
*Homebound/hospice* ***2.08%***

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| Program Area | Students Served | Percent |
|---|---|---|
| TOTAL | 82,647 | 100.0% |

**CONSUMER SURVEY:**

The consumer satisfaction survey conducted in the Summer of 1988 provided information about 124 children enrolled in educational programs. The survey found:

- Satisfaction levels for children with developmental disabilities ranged as low as 71 percent for special day school.
- Satisfaction levels for children with physical or emotional disabilities ranged from a low of 83 percent for regular classroom services to a high of 100 percent for vocational-educational services.
- Dissatisfaction was expressed with special day school services which were unsuited or inappropriate to personal needs of respondents.

Jenny and her pal Sarah exercise each morning in the school gym.

## Critical Indicators For The Future

As a part of the consumer satisfaction survey, 39 parents or family members of school-age children completed a checklist entitled, *Test Your School's IQ: Integration Quotient.* The survey found that the level of commitment to integration at the administrative and policy levels was greater than the level of actual integration activities in the schools.

- Two-thirds of the schools had demonstrated leadership in promoting integration and offering inservice training on integration values and implementation techniques.
- Over 53 percent of the children did not attend school in a typical setting and 74 percent did not use the same transportation as children who were not disabled.
- Twenty-one of the 39 children did receive support in settings with students who are not disabled, led by support staff, modified curriculum, and peer/buddy support.
- Over 56 percent did not participate in extracurricular activities with students who were not disabled, but 52 percent did receive instruction in the community regarding independent living, leisure, or jobs.
- Children with disabilities spent less than two hours per day with students who were not disabled. Sixteen of the 39 children were not in any integrated activities.

Another component of the consumer satisfaction survey was the completion of the *Guidelines for Quality Individual Plans* for 37 students. The short questionnaire contained questions about current state-of-the-art criteria (age-appropriate, community-referenced, functional, generalization, and self-choice). The results show a scattering of effectiveness, but overall, a weak application of these criteria to objectives in education plans:

- 22 percent of the students had age-appropriate objectives.
- 30 percent of the students participated in activities in community settings.
- 30 percent of the students interacted with peers who were not disabled.
- 35 percent of the students had expressed choice about their educational objectives.

### *PUBLIC TESTIMONY*

*"As Developmental Activity Centers phase out early childhood programs, many families are frustrated by the transition. The schools do not have the resources to maintain the same quality of services."*

*"There are mentor/friendship programs in the schools which foster greater integration. People with developmental disabilities volunteer alongside others who do not have disabilities."*

*"The educational system is life threatening to students when staff incorrectly identify epilepsy as behavior problems."*

*"I am amazed that the [Minnesota] educational system is the oldest and most established; yet parents have their hearts carved out to get services. Why can't schools do it right? Why do we have to fight to be heard?"*

*"Regular education teachers must be mandated to understand exceptionality. When a problem is diagnosed, little communication exists between regular education and special education."*

*"The school board here is awful. They refuse to integrate. Persons in charge of the special education programs have their own ideas of what is right, and it is 20 years behind the times."*

## Recommendations

We must develop and implement COMPREHENSIVE INCLUSIVE LEARNING for persons with disabilities, that underscores a fundamental commitment to:

- Transforming the services which are in place for children and young people (birth to age 21) to make them available, accessible, and supportive to all children and young people, regardless of type or severity of disability;
- Ensuring that children and young people receive a quality education and the opportunity to develop relationships and a sense of belonging with other children;
- Welcoming all children into typical classrooms of their neighborhood schools. We must determine *how* to support a child in typical settings and make those settings socially and physically accessible to all children. The question is not *if* a child can be supported, but which measures will be required to ensure that the child is supported. Such a commitment means a policy of "most enhancing environment" rather than "least restrictive;"
- Establishing curriculum and integration strategies that prepare students with disabilities to live, learn, work, play and participate in the adult world; and
- Developing staff training and support for administrative and teaching personnel to ensure that typical teachers receive the knowledge and support necessary to include all children in their classrooms.
- Lifelong learning is important for all people, and such options as vocational technical, community college, and university classes should be available for persons with developmental disabilities.

Denis and his job coach Darlene touch base now only once a week

In *A New Way of Thinking* we said that real work meant earning a living, being productive and making a contribution to our community. The relationships we develop with people with whom we work are important to us.

We used to spend years preparing people with disabilities for eventual work or providing them with sheltered places in which to work. In Minnesota and many other communities, we have learned that by focusing on preparing people for work, we have often created circumstances that result in people never actually getting jobs.

Today we know that if we support individuals to find jobs, we can effectively teach them the necessary skills for that job and make adaptations to the work place that increase their ability to do the job. We have learned that if we assist people to find, obtain and retain employment, they, as well as society, experience significant benefits.

## Where We Are

In 1988, employment services offered to Minnesotans with developmental disabilities were primarily offered through the Division of Rehabilitation Services:

**Work component services:**

- Provided in developmental achievement centers through agreements with rehabilitation facilities.
- 13 programs, 1,370 people served.

**Work activity centers:**

- Provided structured activities for which wages are paid.
- 23 programs, 1,874 people served.

**Long-term extended employment:**

- Paid employment for an indefinite period of time for people with severe disabilities who are unable to meet production standards required in competitive employment. The work is done in a sheltered setting.
- 25 programs, 3,294 people served.

**Community based employment:**

- Employment at minimum wage or above for 30 hours or more per week, in typical community work locations.
- 30 programs, 3,363 people served.

Another large source of vocational activity is provided by Day Training and Habilitation Services (DTHs) under the Department of Human Services. These services provide training, habilitation, and/or supported employment on a regular basis to people with developmental disabilities outside their place of residence.

- In 1988, there were 5,625 adults who received services from Day Training and Habilitation Service providers.
- Of these adults, 4,306 worked in-house. Average hours worked per week was 7.5 with an average hourly wage of $0.62.
- Integrated employment activities were provided to 1,675 adults. Employees worked an average of 8.1 hours per week, at an average hourly wage of $2.18. Nearly 62 percent of these persons worked in either general cleaning or restaurant/fast food services.

In 1988, there were 1,787 persons in supported employment, 1,609 from programs sponsored by the Division of Rehabilitation Services and 178 who met the definition from programs sponsored by the Department of Human Services.

The number of persons eligible and receiving benefits from Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and SSI state supplement is less than could be. Average SSI monthly benefits in 1987 were $197.80 compared to a national average of $218.39.

Minnesota participation in SSI and SSDI programs lags behind national averages. For example, Minnesota ranks 47th in SSI participation.

**CONSUMER SURVEY:**

The consumer satisfaction survey received information about 60 adults who were working. Eighty-five percent of the persons with developmental disabilities who responded to the survey were employed compared to thirty-seven percent of the respondents with physical and emotional disabilities.

- Twenty percent of persons with developmental disabilities worked in private business,while eighty percent worked in rehabilitation facilities. Fifty-two percent of persons with physical and emotional disabilities worked in private business, while 48 percent worked in a sheltered settings.
- Average hours worked per week was 25.5 for persons with developmental disabilities and 17.0 for persons with emotional or physical disabilities.
- Average hourly wage was $3.47 for persons with emotional or physical disabilities and $2.05 for persons with developmental disabilities.
- Integration defined as working with eight or fewer persons who are nondisabled, was reported for 37 percent of persons with developmental disabilities and 56 percent of persons with physical or emotional disabilities.
- Satisfaction with work ranged from a low of 72 percent for adults with physical and emotional disabilities and 86 percent for persons with developmental disabilities.
- Persons with physical and emotional disabilities expressed concern about rehabilitation services. An equal number expressed dissatisfaction and satisfaction with such services. Comments included a desire for summer work programs, vocational oriented activities at an earlier age, better paying jobs, and jobs targeted for persons with mental illness.

### *PUBLIC TESTIMONY*

*"There is a need for supported employment. There is a need for full-time meaningful employment, not busy work. Five to six hour jobs are needed, not two or three hours a day."*

*"Employment opportunities must increase, but there must be a plan for follow-up supervision to ensure long-term job success."*

*"Employment is the number one problem for people with epilepsy. Five cases of discrimination by the private sector were presented. Laws can be on the books, but so what?"*

*"Persons with severe physical disabilities are fully capable of being successfully employed when appropriate accommodations are made. The trick to staying employed, however, is earning a sufficient salary to pay the going market rate for personal care services. On the other hand, publicly financed assistance programs disappear as a person's income level increases, and then exceeds the limits set for that particular program."*

*"As I understand the days of the Depression, many people had to work hard for long hours for very little pay. I'm in that kind of situation. I would like to live alone, but can't afford rent at $200 per month without having a roommate to share the expenses. People need to give us a chance."*

*"More money is needed for community-based employment, training and follow-up services. Do not decrease in-house sheltered workshop financial support to do this."*

## Critical Indicators for the Future

**Real work for real wages** is a consistent demand from individuals with diabilities. Key questions for the future include:

- **Meaningful Work**—is the work you are doing viewed as real work? If you did not do it, would a person who was not disabled do it, or would it go undone? Do you and others see this work as contributing to the life of the community? Could you work a full day if you chose to?
- **Integrated Settings**—how many other people with disabilities are there at your place of work? Are you seen as an individual, or are you seen as "just another of our handicapped people?" Are you considered an employee or client?
- **Pay**—are you paid a fair wage for the work you do? Are you paid a wage that is similar to persons who are not disabled in a similar position? Do you receive a just and fair wage for your skills and abilities? Do you receive adequate wages to live on?
- **Security**—do you expect to have this job as long as you want it? Will you get the support you need to find a new job or a different kind of work if you need or want a change?
- **Relationships**—do you have the opportunity to get to know and develop relationships with workers who are not disabled? Does anyone assist you to get to know people at work? Do you have the chance to spend time with the people with whom you work when you are not working (either at work or away from it)?

## Recommendations

We must develop and implement COMPREHENSIVE EMPLOYMENT PROGRAMS for persons with disabilities that:

- Emphasizes our commitment to meaningful work, in integrated settings, for equitable pay, in an atmosphere of job and support security, with the opportunity for relationships for all adults, regardless of type or severity of disability,
- Recognizes that individual citizens, including those with disabilities, have a fundamental responsibility to contribute to the social and economic life of the community,
- Recognizes that day and vocational programs must ensure that individuals discover the unique contributions they can bring to the community, and are supported to make those contributions,
- Recognizes that community organizations (businesses, associational groups, recreational and leisure organizations, etc.) should welcome and support citizens with disabilities to contribute and participate in the activities of those organizations,
- Develops employment and support options in generic community locations, and organizations for individuals who are currently unserved and underserved, rather than placing such individuals in existing services when such services do not respond to their needs, and
- Provides for age-appropriate retirement.

Linda goes to the library to read the magazines and be with people almost every day.

Persons with developmental disabilities and their families often require specialized lifelong assistance, provided in a coordinated manner by many agencies and others, in order to meet their needs and eliminate barriers to service.

Public Law 100-146 defined **case management** as a potentially lifelong, goal-oriented process for coordinating a range of assistance for persons with disabilities. Assistance is designed to ensure accessibility of services, continuity of supports, and accountability; it ensures that the maximum potential of persons is attained.

We said in *A New Way of Thinking* that case management is necessary to broker and manage the process of delivering services to people with developmental disabilities. The system must work for the individual and the case manager's responsibility is to ensure that it does.

## PUBLIC TESTIMONY

*"Social workers are overworked. We do not use the social worker. We do it ourselves."*

*"Rule 185 is good in theory but not in practice. Too much paperwork does not result in better services for the individual."*

*"How can a case manager develop good plans and follow through with a caseload of 130? How can case managers hold providers accountable if the case manager does not know the person?"*

*"Case management is one of the most critical pieces in the comprehensive array of services, yet it is one of the weakest pieces. Case managers have inadequate information and high caseloads that prohibit them from providing quality case management services. Parents have low expectations of case management services. There continues to be a huge need for education, training, and the development of new models to improve the delivery of case management services in Minnesota."*

## Where We Are

Since 1981, a series of reviews and evaluations have consistently found that case managers should have fewer persons on their caseloads (recommended ratios varied from 1:25 to 1:30) and more individual contact. Findings also point to a need for case managers who are better qualified and receive more training.

A recent study of case management services by the University of Minnesota, funded by the Minnesota Governor's Planning Council on Developmental Disabilities, verified the 1981 findings as still true:

- The caseload size ranges from 16 to 241 persons. In terms of persons with developmental disabilities, the range is 8 to 196. The average caseload is over 68, more than double the recommended ratio of 1:30. The total number of people on the caseload was 15,000 in 1986.
- Many case managers have not been prepared to perform the functions required by Rule 185 during the process of change from counseling and advising roles to those of team planning, negotiation, coordination, and advocacy.
- The greatest problem currently facing case managers seems to be the delivery of increased and more effective services while struggling with large caseloads.

A 1988 study commissioned by the Department of Human Services also assessed the average caseload ratio and the adequacy of services. The results were very similar to previous studies:

- The total number of people with developmental disabilities on caseloads increased to 16,912 at the end of June, 1988.
- Average caseloads per case manager decreased to 54.8.
- Compliance with Rule 185 was highly correlated with service quality, informal supports, consumer satisfaction, least restrictive environment, and community integration for a sample of 300 people.
- In a ten county sample, an average of 23 percent of individual habilitation plans were completed; 70 percent of individual service plans were completed.

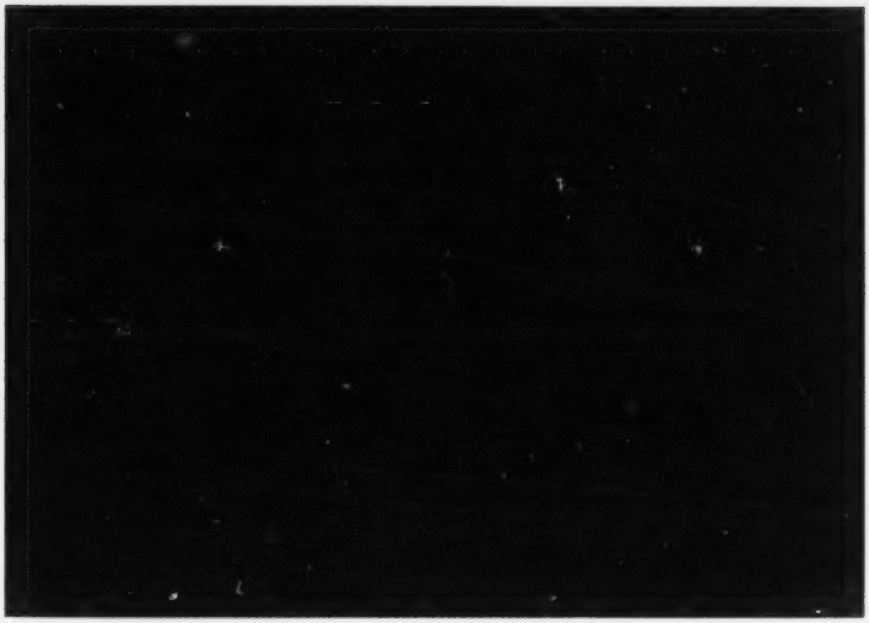
**CONSUMER SURVEY:**

The consumer satisfaction survey revealed the following results about case management services:

- Of the 242 persons surveyed, 115 had been assessed for services. Seventy-six percent of the individuals were satisfied with their assessment.
- In terms of information and referral provided by a case manager, 64 persons had received such assistance and 68.8 percent were satisfied with services.
- Case management services were received by 148 persons and 65.5 percent of the individuals were satisfied with their case management.

## Critical Indicators for the Future

Individuals who have "cases being managed" need to ask the following questions:



## Recommendations

Recognizing the significant role of QUALITY CASE MANAGEMENT services in transforming the system to ensure independence, productivity, and inclusion for all people with disabilities, we believe that the caseloads, training, and mandate of case managers should be brought into line (in policy and practice) with the standards of best practice.

- The services of case managers should be made available to anyone in need of support, regardless of type or severity of disability.
- Individuals and families should be trained and empowered to be their own case managers, relying on case management support when and as required.
- Priority attention should be paid to the development and implementation of new or revised individual plans for people who are currently unserved or underserved, rather than continuing to tolerate their situations of no service or inappropriate service.
- The term "case management" will be replaced in the next few years, by terms that focus on individuals and service coordination.

### PUBLIC TESTIMONY

*"Current state and federal policies, along with the advent of newer, more expensive high technology, creates serious backlogs for the approval of and subsequent delivery of assistive technology."*

*"If a statewide delivery system was present, it would be easier for persons with disabilities to be made aware of the technology that is available to make their lives easier, as well as providing the resources necessary to make it a reality."*

*"Technology has made it possible for us to express our ideas and feelings and let you discover that we do have things to say. Computer technology is one of the most important keys in making a person with a disability become more productive and independent."*

We can be very clear about availability of services. Services which enhance the independence, integration and productivity of people with developmental disabilities are currently unavailable to the following individuals:

- people who are living in congregate facilities,
- young people who are attending special schools,
- adults who are currently attending congregated, segregated day programs, and
- adults who are currently involved with case managers who because of their caseloads and lack of training are unable to provide the service they are mandated to provide.

In other words, these individuals are receiving services that do not enhance independence, integration and productivity. These individuals are, therefore, underserved and unserved.

## Availability of Specific/Generic Services

The public hearings, consumer satisfaction survey, and our own analysis of the current situation indicate that there are **serious problems in the availability of both categorical and generic services in the following areas**:

TRANSPORTATION
RECREATION
PERSONAL SUPPORT SERVICES
TECHNOLOGY

### TRANSPORTATION:

Transportation was one of the greatest problems citied in the consumer satisfaction survey. The two most common types of transportation used were rides from parents or relatives, and vehicles designated to transport persons with developmental disabilities. Public transportation is not being used to the greatest extent possible. Of children, 85 percent wanted more transportation services, while 72 percent of adults wanted more services. Often the desire for more transportation was linked to inclusion in community and leisure activities.

Transportation services in Minnesota have serious limitations, including:

- limited service areas,
- low income limits transit options,
- limited hours,
- difficulty in scheduling,
- existing vehicles are not being used to the greatest extent possible, and
- coordination among various service providers is not a high priority.

### RECREATION:

Recreation should be a part of all people's lives. Satisfaction with leisure and leisure activities for children was 65 percent. Dissatisfaction centered around a lack of friends and a lack of activities. The median number of friends for children with disabilities was one, but 39 percent of the children had no friends. Adults with disabilities on average had more friends, 2, but 31 percent had no friends. Recreation often was of limited nature for most adults, such as television or playing cards.

### PERSONAL SUPPORT SERVICES:

There are serious deficits in the availability of personal support services for individuals who can appropriately be considered developmentally disabled and for many other Minnesotans who have limitations in these activities.

In 1985, there were 2,356 new persons served by three Independent Living Centers in Minnesota, located in Rochester, Marshall, and the Twin Cities. In 1988, there were five centers which served a total of 2,428 new people. The individuals who were served by the centers have many different types of disabilities, ranging from cerebral palsy, spinal cord injury, multiple sclerosis, to others such as visual and hearing impairments, mental illness, orthopedic impairments, and mental retardation.

**ASSISTIVE TECHNOLOGY:**

The Minnesota Governor's Advisory Council on Technology for People with Disabilities, completed two statewide surveys and five public hearings to identify problems and individual needs for assistive technology. The results showed that 100 percent of the respondents could benefit from the use of assistive technology:

- Forty-one percent of the respondents indicated that they did not know where to obtain assistive technology devices.
- Eighty-five percent who were not using assistive devices cited prohibitive cost as the primary reason.
- Eighty percent indicated that they had not attended any training sessions about assistive technology.
- Sixty-one percent had "no, slight, or somewhat limited" understanding of assistive technology devices and what they can do for individuals with disabilities.

In response to many of the needs and issues identified in the surveys and public hearings, the Minnesota Governor's Advisory Council on Technology for People with Disabilities applied for a U.S. Department of Education grant. Minnesota is one of nine states to receive $1.5 million during the next three years.

## Recommendations

The development and implementation of COMPREHENSIVE PERSONAL SUPPORT SERVICES for persons with developmental disabilities includes several features:

- The goals of support to individuals should be seen and mandated as integration, independence, and productivity, but equally important are interdependence, contribution to the social and economic life of the community, participation, friendships, relationships, dignity and respect.
- Social, physical and fiscal access to such support services and programs as Family Subsidy, Semi-Independent Living, Home and Community Based Waiver, and case management should be extended to individuals who are unserved and underserved, including people with physical disabilities, emotional problems, and sensory impairments.
- Policies and practices should be developed to enable and empower individuals and families to purchase the supports and assistive technology required from specialized providers and generic community resources.
- The recognition in policy and adequate funding that people with disabilities have the right of access and opportunity to housing, employment, transportation, recreational and leisure, and general activities of the community.
- The development of a cultural understanding in Minnesota of the critical role that ordinary citizens and generic community organizations should play in the lives of people with disabilities. In other words, Minnesotans should come to assume that people with disabilities are people with whom they can develop relationships, obligations and interactions. Minnesotans should come to assume that people with disabilities are members of the community and belong in the places and with the people of the community.

As we have seen, there continues to be a wide gap between what we know to be both possible and desirable for people with developmental disabilities, and the situations in which they currently find themselves. There is a policy gap between what is important and what is being delivered to people.

To bridge that gap requires a great deal. One of the primary requirements, however, is to build a system which is truly accountable to the person with a developmental disability. Accountability implies power. Accountability to the person implies that the person has power.

We need to explore some of the ways in which individuals are empowered — to have control over their own lives, and to hold services and systems which have a great deal to do with their lives accountable for what they do.

## Dimensions of Power and Accountability

An accountable system is our goal. Power to individuals and families is a primary vehicle for achieving the goal.

Individual and family power has a number of ingredients:

- **System responsiveness:** A system designed to respond to individuals, to be driven by plans developed to increase the person's integration, independence, and productivity.
- **The individual's community:** A community of people: family, friends, and advocates which enable the individual and the family to develop a vision of what they want and how to get it.
- **Support to individuals:** The presence of supports in the individual's life which enable the individual to be present and participate in the community.
- **Concerted action:** A coalition or network of individuals with disabilities, family members, and allies who support one another in achieving a common vision.

Accountability must exist in four phases of receiving support:

ASSESSMENT
PLANNING
PROVIDING SUPPORT
EVALUATION

**ASSESSMENT:**

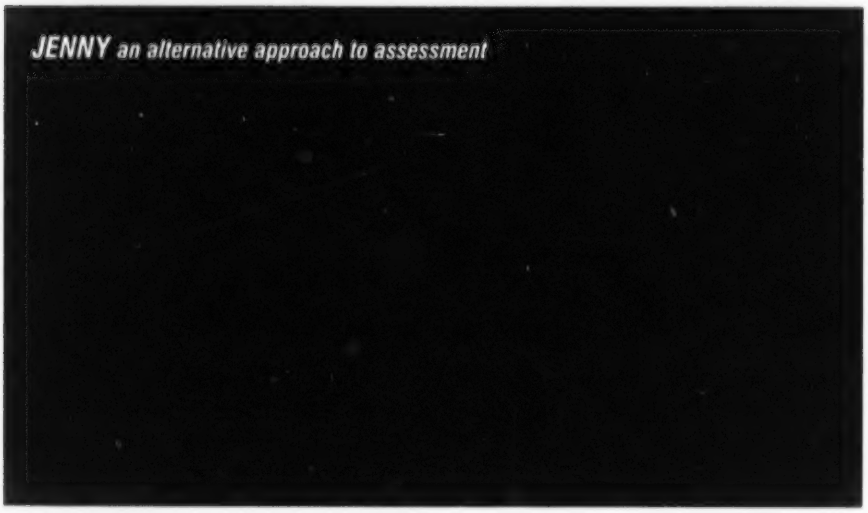
The individual, family, and friends (people who know the individual best and intimately) are fundamentally responsible for identifying the individual's strengths, needs, preferences, gifts, and talents. This assessment process may be aided by professionals who help in the process of clarification and understanding. The purpose of the assessment is to get a clear understanding of the individual, not to describe the person in a series of negative clinical terms. The assessment identifies the individual's gifts and talents, so that they can be built upon, and needs, so that they can be met.

The goal of the assessment process is to assist the individual:

- To belong to the community (integration);
- To be responsible for as much of one's life as possible (independence); and
- To contribute to the life of the community (productivity).

**The fundamental accountability issues at the point of assessment are:**

- **Does the assessment portray an individual with strengths, gifts, and capacities?**
- **Are the descriptions of the individual positive and useful?**
- **Do the descriptions present the individual as a whole person with a life to lead and a future to build?**




**PLANNING:**

The development of individual plans is a powerful process. On the surface, plans contain objectives for individual service, habilitation, education and transition. But, in a very real sense, the plan articulates a vision of the individual's future — hopes and dreams, and what will be required to fulfill them. The plan also articulates the demands and expectations to which others — services, community, friends — will be expected to respond.

A plan belongs to the person, not the system. It is the individual's plan for the future. The plan is empowered to guide action. It, not the existing system, is the point of reference.

**The fundamental accountability issues at the point of planning are:**

- **Whose plan is it? The person's or the system's?**
- **Does the plan describe the ways and means of shaping the world to support the individual or of how the individual will be shaped to fit the system?**
- **Does the plan describe the kind of life the individual wants to lead or is it a description of a life in services?**

Minnesota statutes and rules require the development of individual plans. **It does not require individuals and families to think only in the terms of plans**. What can individuals and families do?

- **Develop your own plan** — use your own forms and ways of thinking.
- **Invite the case manager to help you translate your dream into the language of forms**.
- **Make sure the translation maintains the integrity of your dream**.
- **Think about all aspects of life** — You don't have to share it with services, but it is a good idea to know how all the pieces will fit for you.
- **Make sure that team meetings are meetings of your team** — If professionals treat you as a guest at the meeting, remind them that they are working on your behalf. Invite as many friends, relatives, and fellow travelers as there are professionals.
- **Let others know how satisfied you are with the planning process** — Fill out an evaluation of the team meeting, send it to the agency or a third party.

The approval of plans invokes many systems issues — funding, policy, principles, and so on. This is a part of the negotiation process for plan approval. It should not be a predeterminer of plan content.

**PROVIDING SUPPORT:**

Providing support requires marshalling and applying the resources to fulfill the plan.

One of the bigger problems with the way we go about providing support is that we look at the world only in terms of services. Life comes to be defined as living, learning, working, and playing in special services.

Federal law describes case management, for instance, in terms of coordinating the range of assistance needed by persons with developmental disabilities and their families. The key word here is "assistance." Assistance implies services, but it also involves support, technology, and aid.

"Services" are usually supports delivered by professionals and staff. "Assistance" has a much broader meaning. The way we usually describe things is in terms of services needed by the person, and in some cases, services needed by the family. The term "services" evokes images of facilities, staff, curriculum, and buildings.

The way that most families and individuals would like to think about life has little to do with services. It has a great deal to do with the "feel" of the places where the individual spends time, and a sense of security, a sense of belonging in the real world.

A great deal hangs on the words we use. Even more hangs on how words shape our dream and how the support fulfills our dreams.

Most individuals and family members are aware that dreams for the future rarely look or sound like the content of an individual service plan or the systematic protocols of individual habilitation plans.

**The fundamental accountability issues at the point of providing support are**:

- **How closely do the supports provided match the original plan?** Are services adapted to the individual, or is individual need compromised to meet the current approaches and capabilities of the service?
- **How is funding allocated?** Is funding allocated based on the requirements of individual plans, or based on service requirements regardless of the specific needs of individuals in those services?
- **Do supports increase the individual's inclusion through presence and participation in the community?** Or do services involve meeting performance objectives for the individual in isolation from the community?
- **Do supports involve meeting performance objectives for the agency or for the individual?** Whose performance is at issue — the agency's in support of the individual, or the individual's in terms of meeting the agency's objectives?
- **Do the supports and services involved in an individual's life work together to make sense?** Or do compromises with each agency result in a disjointed life for the individual?

We suggest the following steps to promote accountability in fulfilling individual plans:

- **A voucher system:** Allocate funds to the individual (directly or indirectly). Charges are made against the individual's account as supports are purchased from agencies or individuals.
- **Performance contracting to improve individual outcomes**: Allocate funds based on achieving outcomes for the individual, rather than simply providing a service or support.
- **Enable case mangers to achieve plan implementation (reduce caseloads)**: Set caseload limits at a level which allows case managers to be more actively involved in not only identifying existing programs, but adapting them to meet the individual's needs, and developing new supports.

**EVALUATION:**

Curently, evaluation and monitoring focus primarily on the general performance and compliance of agencies and services. By and large, the issues are effectiveness and efficiency at the group level.

These issues are important, but **the fundamental accountability issues at the level of evaluation are**:

- **Are desired outcomes achieved by, for, and with the individual?**
- **Are the general criteria embedded in standards and regulations relevant to the individual?**
- **Are specific criteria based on outcomes specified in an individual plan?**

KYLE an alternative approach to evaluation

Preference of the individual must be respected. It requires that individuals, and those closest to them, devote significant time and energy to determining what is needed, and to ensuring that what is provided is, in fact, what is needed.

It is important that individuals express their views on the statements, actions, and responses of others. It may be necessary for the individual to express these views in many contexts — discussion, negotiation, conciliation, confrontation, advocacy, and vigilance.

Having preferences and taking action are major steps with a number of dimensions for each individual:

- The ability of the individual to communicate and others to listen.
- The ability of the individual to form opinions and for others to appreciate those opinions.
- The respect accorded the individual by others.
- The extent to which others allow the individual to express choices.
- Time and energy.
- Assertiveness.

Many individuals with disabilities will rely on others who are trusted and close to them to hear and give expression to their views. Individuals, however, should be assisted in making choices and taking action, with or without the support of those close to them.

We recommend the following steps to enrich accountability in evaluation:

- Friends and family as monitors: Ensure that there are people who are close to the individual (rather than paid to be) involved in the regular monitoring and evaluation of plan implementation.
- A checklist system: Have consumers and families use simple, but powerful, checklists (similar to those we highlighted earlier) to monitor and evaluate services.
- An objective third party: Identify an objective third party who can receive completed evaluations from individuals, families, and advocates regarding the quality of assessment, planning, and implementation. Have the third party create regular reports on the system's quality and report findings to state agencies, services, and advocacy organizations.

## The Need For Concerted Action In Common Cause

The truisms implicated in this discussion of accountability form a long list. This list certainly includes the following:

- It is not easy. It will never be easy, especially for people who are unserved or underserved.
- To achieve and maintain accountable systems requires constant vigilance and ongoing advocacy.
- The broader the base of power individuals and groups have, the greater impact they will have.
- The issue of inclusion cuts across all disability groups.

In a world or system based on accountability to the individual, the individual's base of power is himself or herself. Until such a system is achieved, however, concerted action by individuals joined in common cause will be necessary.

***"Individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society."***

***(Americans with Disabilities Act, 1989)***



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